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ABSTRACT

The document looks at the continuum of residential service models for mentally retarded individuals. Chapter 1 describes and cites research on four models (natural family homes, foster homes, community residential facilities, and nursing homes); and points out differences among these service models. A second chapter focuses on programs and facilities for children with sections addressing natural families (the Minnesota Family Subsidy Program, Certified Foster Parents); foster homes (Community Training Homes, the Pittsburgh Program, Ramsey County Program); recruitment of foster parents; and community based group homes (Working Organization for Retarded Children, Pan American Homes of Pennsylvania, Lynch Homes). Chapter 3 reviews three community based programs for adolescents and young adults--Concerned Care Inc.,; Group Live-In Experience; and the Hartford Group Homes. A fourth chapter looks at two group home programs (New Concepts for the Handicapped Foundation and Macomb-Okland Regional Center) and an apartment living facility (the Hartford Apartments) for adults. Chapter 5 lists future trends and critical concerns of residential services for the retarded; a final chapter cites references. (SB)

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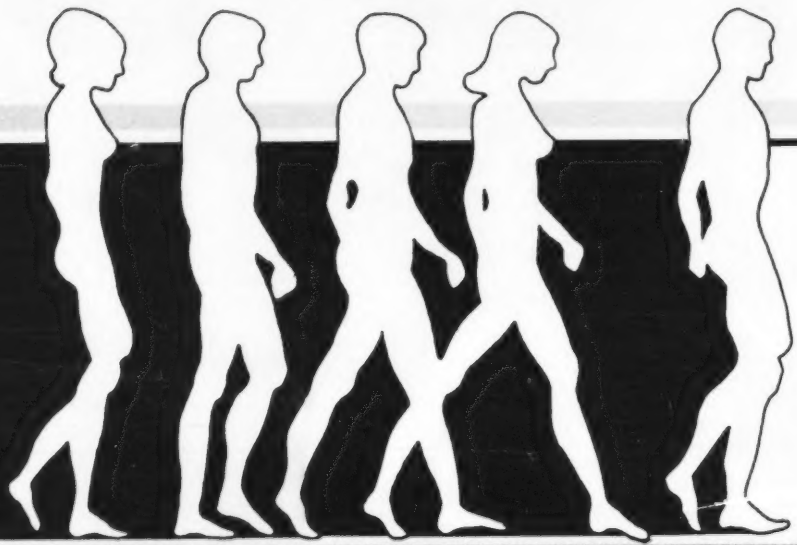
Bridges

EXAMPLES OF COMMUNITY RESIDENTIAL PROGRAMS VOLUME 2



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1 INTRODUCTION

Many mentally retarded citizens require specialized residential services due to the nature of their handicapping condition. This group includes most severely and profoundly retarded persons as well as a number of people who are moderately retarded. Some individuals need highly structured residential programs, while others need only minimal supervision and occasional assistance with social and economic survival skills. A few people will require skilled nursing care due to severe neurological handicaps or physical disabilities.

No single type of service is suitable for every person in need of a supervised living arrangement. However, all retarded citizens, regardless of the degree of handicap, can benefit from consistent interpersonal relationships which can be provided in a variety of service delivery models, four of which are described below.

Natural Family Home

The retarded individual's natural home is one of the most important options in the continuum of residential services. However, several factors influence a family's ability to keep their retarded son or daughter within the home, including:

- the family's financial resources (it is more expensive to rear a handicapped individual)

- the availability and accessibility of specialized or generic community services to help a family meet the needs of its retarded member
- the family's psychological and physical ability to cope with having a retarded person in the home
- the severity of a child's handicap (e.g., physical handicap, severe behavior disturbance or serious health-related problems which require medical supervision)
- the age of the retarded person and the possibility of his moving out on his own when he reaches young adulthood

There are a number of factors which work against keeping the retarded offspring in the home. Perhaps chief among these is the organization of funding streams and eligibility requirements for services. This has been a long-standing concern of the Association for Retarded Citizens (ARC). For example, in November 1978, a resolution was adopted by the delegate body at the Association's annual convention calling for the development of public assistance funds to help maintain mentally retarded people in their natural homes.

Foster Homes

The foster home approach generally involves placing one or two retarded per-

sons in the home of a married couple and paying them a modest stipend to provide family-type care for the residents. It has been popular to think of the foster home concept as being appropriate for meeting the residential needs of children only; however, the results of a recent survey (Bruininks, Hill & Thorsheim, 1980), indicated that this approach is actually serving more adults than children. Of the approximately 5,000 residents who were involved in the study, 69 percent were over 21 years of age, 19 percent were 15 to 21 years old, and 12 percent were under the age of 15 years.

The results of the survey disclosed that approximately 33 percent of these foster home residents were severely or profoundly retarded, 38 percent were moderately and 21 percent were mildly retarded. Eight percent were not mentally retarded. The number of residents per foster home ranged from one to 14, with an average of 2.6.

The majority of foster homes surveyed indicated admission requirements which included the resident's being toilet trained, ambulatory, not having behavioral problems, being involved in day programs or employed, and understanding language.

Community Residential Facilities

One of the most thorough studies of community residential services has been carried out through the Developmental Disabilities Project on Residential Services and Community Adjustment (1978) by Robert Bruininks and colleagues at the University of Minnesota. In the Project's Brief #2, a community residential facility is defined as follows:

"Any community-based living quarter(s) which provides 24-hour, 7-days-a-week responsibility for room, board and supervision of mentally retarded persons, with the exception of (a) single family homes providing services to a relative; (b) nursing homes, boarding homes and foster homes that are not formally state licensed or contracted as mental retardation service providers; and (c) independent living (apartment) programs which have no staff residing in the same facility."

Bruininks found 37 different types of community residential facilities fitting this definition. Although this category of residential facility is most often referred to as a group home, there is no standard classification scheme to define this wide range of residential services. The size of community facilities identified by Bruininks and his co-workers ranged from one to 942 residents, with an average of 17 residents per facility. Discounting the few excessively large residential settings, the most frequent number of residents per facility was six. Over 88 percent of the community facilities served fewer than 21 residents.

Considering the level of retardation, Bruininks and his colleagues (Bruininks, Hauber & Kudla, 1979) reported that a majority of persons living in community facilities were mildly or moderately retarded, although about 32 percent of the residents were classified as severely or profoundly retarded. It was also discovered that over half of the residents

in community facilities were multiply handicapped, with the following cited as the most frequent handicaps: behavior disorders (19%); epilepsy (18%); cerebral palsy (9%); blindness (3%); autistic-like disorders (3%); and deafness (3%). More than 19 percent of these residents had two or more handicaps in addition to mental retardation.

Staffing of group homes is another area of wide variance. Group homes may have live-in staff members, rotating staff who work in shifts, part-time counselors, or supervisors who simply check on residents either daily, weekly or monthly — all depending upon the residents' needs for supervision and assistance.

Some group homes are conceived as a permanent residence for those individuals admitted to their programs, while others have strict policies limiting the time an individual can live there. These limits may relate to age, health status, vocational or other developmental skills.

Nursing Homes

Nursing homes probably share more common characteristics with one another than any other type of residential approach. Nursing homes tend to be medically oriented because their clients have health problems serious enough to require 24-hour nursing supervision and services. Also, the laws and regulations governing the licensing and operation of nursing homes are more commonly standardized at federal, state and local levels than those governing some other types of residential facilities. Therefore, most nursing homes are required to meet a lengthy list of standards related to the structure and design of buildings, professional staffing patterns, recordskeeping and safety measures. There are, of course, some major differences among the programs provided by nursing homes.

In order to qualify for ICF/MR Title XIX funds,* an increasing number of nursing homes are introducing rather sophisticated programs to meet the developmental needs of mentally retarded individuals. However, the vast majority of nursing homes continue to be primarily treatment-oriented in the medical sense.

Differences Among the Service Models

There are at least three major criteria for categorizing different residential service needs. Consideration of the individual's age, developmental level or health status can provide a framework for thinking about different approaches to providing residential services. There are specific program and professional concerns for each of these three considerations. In order to provide some logical framework within this publication for discussing residential programs at the community level, the various types of service models have been organized according to age groupings.

*An ICF/MR may refer to a ward or unit in a large state institution, a nursing home or any one of a variety of group homes. The term ICF/MR refers only to a particular source of funds (i.e., Medicaid) and not necessarily to a specific model of service.

2

PROGRAMS AND FACILITIES FOR CHILDREN

The design of programs and facilities for mentally retarded children will depend upon their specific individual needs, including:

- current level of development
- health status and need for medical supervision
- educational needs
- extent of behavioral problems
- adult-child relationships
- interaction with family and community

Mentally retarded children, like their non-retarded peers, need an environment which will provide adequate and appropriate stimulation for personality growth and skill development, whether it is the natural home or some other setting. Thus, residential environments should be designed to encourage learning and independence. This may involve making the physical surroundings accessible (e.g., providing appropriately sized tables and chairs and making bathroom fixtures and toilets usable) or modifying the home (e.g., installing rails, ramps and other specialized equipment) to compensate for physical handicaps.

Children easily become dehydrated when ill or when staff are unaware of the amount of fluid they are receiving. In situations where children are non-ambulatory or unable to get water on their own, parents or staff must remain constantly

aware of the children's needs for adequate fluids. Simply providing fluids at mealtime is not sufficient. The child who becomes slightly dehydrated is an easy victim of infections, constipation and poor food absorption. Health problems can negatively affect the child's ability to participate in learning tasks and thereby reduce his ability to learn new skills.

Since accidents are the number one killer or crippler of children, realistic precautions should be taken to prevent mishaps. Likewise, children should be taught to avoid dangerous situations. The National Safety Council offers several publications which can help parents or staff members to identify dangerous materials around the house and learn how to safely store them in "child-proof" locations. Every home should also have a posted list of dangerous or poisonous materials and the first-aid procedure to be employed in case a child does ingest any of those substances. The phone number of the local poison control center should also be kept near the telephone for emergency use.

The single most important issue in residential programming for children is the quality of the relationship and interaction between the children and the adults who care for them. A consistent and caring relationship between adult and child can make up for a host of other environmental problems. Likewise, if the adult-child relationship is not consistent and caring, it can defeat an otherwise ideal program and environmental structure.

Children who live away from home should maintain a close involvement with the natural family. Such involvement helps children to develop a sense of personal identity and belonging. Successful programs encourage regular family involvement, including visits home and excursions into the community with family members or with personal advocates.

The needs of mentally retarded children can be met through a variety of residential approaches, including the natural home, foster homes, community-based group homes and specialized facilities for the multiply handicapped.

Natural Families

In many communities adequate support services are available only for those families who can afford to pay for them, privately or through public welfare programs. Consequently, gaps in services remain for those middle-income families who cannot afford to pay the high costs of special services, yet do not qualify for most public assistance programs. Even with financial aid provided through Social Security benefits, certain services remain unavailable because of cost. In fact, many states reduce benefits for the individual who lives with the natural family. In their study of natural families, Willer, Intagliata and Wicks (in press) found that physical therapy, speech therapy, transportation, counseling and recreation services were the most frequently mentioned as unavailable because of cost. Few, if any, states have resolved this financial dilemma for families who would prefer to keep

their mentally retarded son or daughter at home if they could afford to provide the needed services. There are, however, some beginning efforts toward solving this problem.

Minnesota Family Subsidy Program. The Minnesota Department of Public Welfare, Mental Retardation Division, has devised and tested a successful support mechanism for the natural home as a residential service option. In 1975, the Minnesota legislature created the Mental Retardation-Family Subsidy Program as a three-year, experimental effort which granted a public subsidy to 50 families to care for their mentally retarded children in the natural or adoptive home. The purpose of this legislation was to test the family subsidy concept as an alternative to placement outside the natural home.

The Family Subsidy Program typically provided families up to $250 per month. Eligibility for the program required parents to have children under the age of 18 years with a primary diagnosis of mental retardation who were living at home, or would be returning to the family from a state institution or from a licensed community residential facility. Subsidy grants to families included the costs for:

- diagnostic assessments, medical expenses and medications
- special diets and special clothing
- special therapeutic equipment
- child care costs
- educational and training programs supplementing school programs, including visiting nurses, therapists and behavior management specialists
- transportation costs

Minnesota's Department of Public Welfare has declared the program to be highly successful. Here are some of the Department's major findings from the study:

(1) Out-of-home placement was prevented for 76 percent of the children in the program.

(2) While the monthly subsidy appeared to meet the needs of 82 percent of the families, approximately 18 percent needed additional assistance ranging from $25 to $150 per month beyond the grant limitations. The subsidy breakdown by category showed that the most dollars were spent for educational programs, special equipment and babysitting.

(3) Based on parental priority ratings, the following services were most needed in order to maintain the child within the home: educational programs, medical services, medications, babysitting, respite care and special equipment.

There were many indirect benefits for the families participating in the subsidy program:

- Family tension and strain were eased.
- Family unity was maintained.
- Psychological support was given to the family, who thus felt that "society" was responsive to their decision to care for their retarded child.

Certified Foster Parents. Another type of subsidy program which is being tried in several states, involves certifying natural parents as foster families. This enables parents to receive foster care funds and thus prevents out-of-home placements.

In New York, this approach is being used to encourage families to take home their institutionalized dependents. If the retarded person has at least a two-year history of institutionalization in a public facility, the natural parents are eligible to receive public welfare and Supplemental Security Income and assistance from foster care staff.

There are many issues to be considered in programs of this nature. It would be highly preferable to develop community service systems which can provide necessary support services to families without their having to deal with all of the red tape associated with certifying the natural home as a foster home. At present, natural parents are required to meet the same certification process as other foster parents and are, therefore, subject to the same monitoring and control by the foster care agency. Many natural families resent giving up some of their rights as parents in order to receive needed services.

Parents frequently suffer many of the same frustrations experienced by professional staff members of group home programs. Willer, Intagliata and Atkinson (1979) found that initially the main problems a family runs into are caused by the retarded person's inappropriate behaviors in the family setting. These include hyperactivity, poor communication, tantrums, anxiety, withdrawal and problems with peers such as aggression, poor social skills and inadequate sexual adjustment. Associated problems include too little free time for parents, parental neglect of other family members because of the extra attention required by the retarded person, and tension caused by visiting relatives who do not understand the situation. Willer and Intagliata's studies conclude, however, that "despite all of the problems, natural families seem fairly satisfied with having their retarded relative return to their homes, and at least 63 percent (of families studied) felt the home would still be their first choice in 10 years' time for that person."

The question of whether or not the natural home is the most beneficial setting for all mentally retarded individuals is also open to considerable debate. There are, without doubt, some situations in which the natural home does not represent the best environment for continued development of either the child or the parents. In these situations, it may be desirable to obtain professional assistance in seeking an alternative placement within the community.

Foster Homes

Foster home programs for mentally retarded individuals are among the most rapidly developing service options in the nation. As an alternative to institutionalization, many states have increased their efforts to place more retarded children and adults into foster care pro-

grams. Much of the current enthusiasm for foster care services is directly related to states' efforts to reduce the populations of public institutions.

There are examples of foster care programs which have high failure rates, as judged by residents who must be returned to the institution. These failures often appear to be directly related to the fact that the programs were expanded too rapidly and before adequate support services were available. Most authorities on foster care are also inclined to agree that additional training and consultant support are essential for foster parents' acceptance of retarded persons. All such services require considerable planning and coordination to be successful. There are, however, many foster programs which have been adequately planned and appear to be highly effective.

Community Training Homes. One of the better known examples of a successful foster care program for retarded persons has been operated by the Macomb-Oakland Regional Center in Michigan since 1973. The Macomb-Oakland program is structured on a foster home model, but the residences are formally called "Community Training Homes."

Gerald Provencal, director of the Macomb-Oakland Regional Center, indicated that the success of a client's adjustment to community placement depends more on the careful preparation of the foster parents than the client. Each foster family is required to participate in both preparatory and continuing education programs. Inservice training for new parents involves five to eight sessions of about three hours each. The topics covered include an orientation to mental retardation, principles of normalization, maintaining safe environments, fire and safety considerations, changing behavior, administrative considerations, leisure time activities and community placement issues. In addition to inservice training, the parents attend monthly meetings to solve problems and improve their parenting skills.

A major component of the Community Training Home progam is that foster families receive supplemental monies for conducting daily training sessions with the client in the home. These training sessions are in addition to regular out-of-home school and vocational programs. Contracts are negotiated with the foster family to spend two hours per day working on four predetermined training objectives for the client. A team of program specialists is available to the foster homes on a 24-hour basis to assist with any problems which might arise. A member of the team visits the home regularly and assists the parents with techniques to achieve the training objectives developed by the team for each client.

The Pittsburgh Program. Another approach to foster care service has been developed by the Family and Children's Service in Pittsburgh (Freeman, 1978). The agency arranges foster home placements for retarded children with severe behavior problems. The major difference between

the Pittsburgh program and traditional foster care approaches is the professionalization of the foster parents. The parents are employed as staff members of the agency, as opposed to functioning as independent contractors who provide services.

According to Freeman, acquiring professional status drastically changes the foster parents' orientation to the agency. They become very involved, work closely with other staff and increase their knowledge about agency resources needed to get their jobs done. The concept of professionalization has resulted in a strong positive response from the foster parents, most of whom had not completed high school.

The Pittsburgh program reports that despite the serious behavioral problems of children in the foster care program (e.g., self-abuse, hyperactivity and lack of communication skills), all but a very few showed increases in intelligence test scores of up to 10 to 11 points. Marked improvement in social skills was also exhibited by more than 90 percent of the children. Several observers, however, have noted that when children are first placed into foster care, there tends to be rapid progress during the initial year, with less dramatic improvement after the first two years.

Freeman also advocates placing two children in each home, and contends that if the children are at different developmental stages, foster parents are less likely to become overprotective. Also, when more than one child is present in the home, foster parents are less likely to feel a sense of failure. When the children are functioning at different levels, at least one child is usually improving at any given time, thus fulfilling the parents' need to be successful.

Ramsey County Program. The Ramsey County Professional Foster Care Program of St. Paul, Minnesota, reports success similar to the Pittsburgh project. Foster families are initially involved in an extensive training program, and then continue to attend training seminars every three or four months. Milt Conrath, director of the Ramsey County program, says he has found that groups of foster parents who go through training together and continue to meet regularly serve as a mutual support group — sharing ideas and helping one another solve problems associated with foster parenting.

In Ramsey County, many of the foster families also provide respite care services. Mr. Conrath indicated that the relationships between these foster families and the natural parents are generally quite good. One foster family may, for example, provide respite care intermittently to the same mentally retarded persons over a period of several years, thus developing a close and positive relationship with the children and the natural parents.

A unique aspect of the Ramsey County foster care program involves the development of a "Life Book" for each foster child. The Life Book is similar to a combination scrapbook and family album. It

documents the life of each child, including photographs, likes, dislikes, accomplishments and the people who play a role in the child's life. Each child has a book and it goes with the individual if there is a transfer to another program or to another foster home. Many foster parents see the book as documenting the quality of their interactions with a child, and it also symbolizes the individual humanity of the child — providing a sense of history and thereby suggesting a future.

Recruiting Foster Parents

The findings of a study (Stone, 1969) dealing with the recruitment of foster parents indicate that about 70 to 80 percent of new recruitments result from contact with other foster parents. So, foster parents themselves appear to be the most fruitful source of recruitment of new foster families. However, the use of publicity in newspapers should not be overlooked as an important element in finding new potential foster families. For example, some programs run regular ads in the "Help Wanted" section of their newspapers.

The Lancaster Office of Mental Retardation in Nebraska tried a unique approach to the use of newspaper publicity (Coyne, 1978). A series of feature stories ran in a local weekly newspaper distributed free to each household in the city. Coyne states, "Each week or two a child needing a foster home was described, with a picture and a personal story about what the child had to offer a prospective foster family. Persons were requested to call the agency for more information. The stories were written to appeal to families who already had children and included such details as the child's favorite vegetable or toy."

The effort accomplished two purposes: It encouraged people to talk to the agency about foster parenthood, and it was a way of introducing mentally retarded children to the community one by one, bringing the community information about the effects of retardation, the differences among such children and their special needs. After more than three years of the regular feature stories, the agency assessed its impact on recruitment of foster parents and discovered that more than half of the new recruits were influenced by the mass media campaign, but that they were most highly influenced by previous contact with other foster parents.

After potential foster parents are recruited, there remains the essential task of providing them special knowledge and skills. There is no general agreement as to what type of training program best prepares people to become foster parents. Several agencies have developed their own approach to training, and these programs vary widely in both method of teaching and in content. Recently, however, the Child Welfare League of America mounted a special project to prepare curriculum materials for foster parenting of retarded children.[1] The specialized course is intended for both new and experienced foster parents.

[1]*Information about the materials can be obtained by writing to: Foster Parent Curriculum Project, Child Welfare League of America, 67 Irving Place, New York, New York 10003.*

Community-Based Group Homes

As noted in an earlier discussion, the term "group home" has been used to describe residential facilities which may vary considerably in terms of the appearance and size of the physical plant, the number of residents and the program approaches which are used. Such variation is evidenced in the following examples:

Working Organization for Retarded Children. The Working Organization for Retarded Children in Flushing, New York, operates several community-based residential programs for children. The organization has opened six non-contiguous apartments, each of which houses three profoundly retarded, non-ambulatory and multiply handicapped youngsters.

The Working Organization provides the different kinds of supportive staff that are needed to attend to the rather complex needs of these youngsters. The staff-to-client ratio is one-to-one during waking hours. There is one house manager in the apartment at night.

The organization also operates a group home in a typical suburban area of Long Island. The home houses eight children, ages 4 to 16 — four boys and four girls. Four of the children came to the program from public institutions and four came from their natural homes. They are classified as severely or profoundly retarded and all are ambulatory, although some have mobility problems. A live-in married couple and additional daytime child care personnel provide a minimum of one staff person for every two children. There is also a night staff person on duty.

Money to buy the house was raised through a capital fund-raising drive. The operating funds come from the State Department of Mental Hygiene and the City Bureau of Child Welfare, and from SSI payments to individual children.

The children attend public school programs during the day. There are also half-day recreational programs on both Saturday and Sunday. In-home programming is provided to develop daily living skills in areas of self-care, socialization and home maintenance.

Pan American Homes of Pennsylvania. Most community living programs are operated by non-profit organizations. Pan American is an example of an agency which is profit-making. It has contracts with 10 counties throughout Pennsylvania with each contract providing up to eight homes. The organization operates approximately 75 homes through these contracts. The programs range from long-term placements to short-term respite care. Each of the counties provides funding for the residences, which may be townhouses, three-bedroom apartments or small suburban houses. However, counties may recover some portion of the costs directly from parents on a sliding fee scale according to their ability to pay. The homes are staffed by a live-in couple or single person. There are also a number of activity aides or relief people who assist the live-in staff.

Lynch Homes. An examination of various approaches currently used to provide residential services to mentally retarded children reveals that most programs have admission restrictions concerning developmental level and/or health status. The Lynch Homes in Philadelphia, Pennsylvania, specialize in services for multiply handicapped children who require an extra measure of health supervision.

Two of the Lynch Homes are operated in much the same way as a foster home. Staff members (usually a married couple) live in typical suburban ranch-style homes with two or three multiply handicapped, non-ambulatory children. The children leave the home during the day to participate in educational programs and are also involved in intensive programs in the home during other parts of the day, evening and weekends. Additional staff consultants and therapists are available for in-home training and to assist the houseparents in carrying out individual program plans. The fragile health status of these children is monitored daily by a registered nurse.

Summary

The advent of funding streams which supply in-home support for the extra costs associated with rearing retarded children is a promising ray of hope for many families. For other families, the consequences of a retarded child in the home may be so overwhelming as to require an out-of-home placement, regardless of the availability of supplemental income. In these instances, either foster care or group home care are alternatives. Both provide the mentally retarded child a home-like environment and a setting in which educational programming received in school can be supplemented and reinforced. And with careful effort, the natural family can be involved in the child's program so as to prevent severing of family ties.

3

PROGRAMS AND FACILITIES FOR ADOLESCENTS AND YOUNG ADULTS

Just as children have special residential needs, adolescents and young adults present a different, but no less critical, set of needs. The mentally retarded adolescent may be slow in maturing emotionally and socially, but physical maturation is not necessarily delayed. The bodily changes associated with puberty can often be a confusing and frightening experience for retarded individuals and their families.

Young adulthood is also a time of coming to terms with self-identity and sorting out a variety of feelings which are often poorly understood by both the retarded individuals and those who care for them. In a sensitive exploration of the service needs and problems of developmentally disabled young adults, Nancy Deibler (1977) points out that some of the difficulties faced by handicapped adults can be traced to their segregated childhood experiences. Many mentally retarded people were involved in programs and facilities which isolated them from their non-retarded peers during the early years of development. As a consequence, some retarded teenagers have never developed relationships with non-handicapped individuals in their own age group and have had no opportunities to exchange thoughts and ideas about their inner feelings. Thus, retarded young people (especially those who are only mildly or moderately retarded) have no way of knowing which of their problems are the result

of **growing up** and which are **particular** to them because of their **disability.**

Increased interaction among retarded and non-retarded young adults is needed in order to provide an opportunity for the exchange of ideas and feelings. Perhaps the increased integration of retarded children in school settings will result in the formation of peer relationships at an early age. Some residential programs for retarded young people have devised ways to encourage rap sessions and discussion groups composed of retarded and non-retarded young adults.

Self-advocacy programs are another approach for enabling mentally retarded persons to develop increased independence and cope with day-to-day problems. The self-advocacy concept involves the retarded individual's learning to represent and protect his own rights and interests and to obtain needed services. This approach was implemented on a large scale in 1974 when more than 500 mentally retarded people banded together to form the organization People First. Since the beginning of this movement in Oregon, a number of local programs have evolved across the country. These programs are providing mentally retarded persons with an opportunity for learning about each other's problems, their rights and responsibilities as citizens, and how to express and assert themselves. For example, the local program, operated by the United ARC of Milwaukee, Wisconsin, has an active self-advocacy group which meets regularly to explore all kinds of problems, both personal and social. The Milwaukee group also writes and publishes its own newsletter.

The popularity of the self-advocacy approach has resulted in the establishment of several state-level projects which assist in the development of a network of local programs. It is important to understand that these efforts are primarily the result of activities of retarded people.

Community-Based Programs

Effective and appropriate residential programs are needed to foster the decision-making capabilities and independence of retarded persons between the ages of approximately 14 and 21 years.

Concerned Care, Inc. Concerned Care of Kansas City, Missouri, operates several group homes for mentaliy retarded adolescents. Through sensitive supervision from the group home staff, the residential programs provide experiences and opportunities which are typically afforded non-retarded teenagers. Each group home, for example, plans and arranges vacations and outings which bring the young people into contact with normal life situations and with non-retarded people involved in the same types of experiences. The residents of one home planned a vacation to the Grand Canyon. The trip included camping out, mountain climbing, preparing meals in outdoor camp areas and generally doing the things most vacationers and sightseers do. The residents took great pride in their activities and they also enjoyed talking about the risks they took and the things they learned during the

trip. The vacation opportunity provided an occasion to discuss a variety of personal and social problems which might otherwise have never come up. The young people were ready to learn because the experience challenged their curiosity and motivated a need to learn new approaches to solving problems.

Concerned Care uses the Teaching-Family Model as the basis for their community-based residential program. The approach is essentially a family-style living arrangement. Each home is operated by a married couple who have been professionally trained in the techniques of behavior modification, with an emphasis on developing community living skills. Four to eight men and women live in a home and learn to interact as a family.

The Teaching-Family Model includes, as a basic ingredient, the concept of self-government in order to encourage residents to become involved in learning to make decisions which affect their lives. The concept of self-government is initiated by residents and staff members participating in structured group discussions. The staff provide verbal praise and encouragement as residents experiment with offering their opinions and suggestions. After approximately six months of this type of training, the residents are able to better assert themselves and become quite involved in planning for the home,

for vacations and for solving problems related to their work settings.

Group Live-in Experience. Those who are served in the Group Live-in Experience (GLIE) program in the South Bronx Section of New York City are former residents of Willowbrook, a state institution which has been ordered by the courts to reduce its population. The GLIE clients are severely or profoundly retarded, non-ambulatory and exhibit symptoms of cerebral palsy. The program occupies two contiguous apartments on each of two floors of a high-rise apartment building in a federally designated poverty area of the city. The program qualifies as an ICF/MR and receives Title XIX funds.

Sister Barbara Eirich, former director of the project, remarks that "consonant with GLIE's philosophy to find community solutions to community problems, the project attempts not only to provide employment for neighborhood residents but also to lend economic support to local merchants. GLIE's belief in the power of community cooperation was greatly reinforced by the overwhelming acceptance of the project by its neighbors, an acceptance often lacking in more stable middle-class areas."

The project's staff were recruited from the immediate community and trained to carry out highly sophisticated behavioral programs based on the work of Foxx and Azrin (1973) and others. The GLIE staff are justifiably proud of their success with the severely handicapped youngsters who, for the most part, were institutionalized for the major part of their lives.

The program emphasizes a normal rhythm of life — arising at a normal hour, leaving home to attend school and returning home for the evening meal. Status differences between staff and residents have been minimized, as meals are eaten together and facilities in the apartment are shared. The GLIE project is a success story of community living for a group of severely and profoundly retarded people who also have multiple handicaps.

The Hartford Group Homes. Preparing institution residents to live as independently as possible in the community is a primary goal of the Hartford Regional Center in Hartford, Connecticut. The Center has developed a series of transitional living arrangements which offer varying degrees of assistance and supervision to the residents.

Two of the Center's group homes serve adolescents. Both are situated in Hartford, and each serves eight residents. The residential programs provide initial training and adjustment for persons coming into the community from the Mansfield Training School, an institution located several miles from Hartford. The residents are gradually prepared to move on to less restrictive environments within the community.

Residents are introduced to a group home through a series of trial placements. A prospective resident will first spend several weekends at a group home. If the weekend placements go well, the retarded person will stay in the group home for a portion or all of the week. Within a period

of about 90 days, the Center makes a decision about whether to place the retarded person full-time in the community facility. As a result of the pre-placement experience, most residents successfully make the transition from the institution to the community, and rarely does anyone return to the institution after an initial adjustment period.

All of the residents participate in day programs away from home. They either attend public school, participate in prevocational or vocational training, or are employed in sheltered or competitive settings. The homes are managed by a live-in couple who serve as surrogate parents.

Summary

The quality and appropriateness of residential programs are particularly important during adolescence and early adulthood. Retarded people making the transition from childhood to adulthood should be afforded every opportunity to maximize their growth and development and to achieve the highest level of independence that is possible. The basic programmatic goal should be to prepare maturing retarded people to effectively live and, if possible, work in the community.

4

PROGRAMS AND FACILITIES FOR ADULTS

In considering residential programs for mentally retarded adults, major concerns include the health status and the developmental, educational and vocational needs of the residents. Those midlife mentally retarded adults who are able to hold jobs in the community need to establish as normal a lifestyle as possible in their daily routines. Many elderly mentally retarded individuals may need extensive medical care and may, under certain circumstances, require a nursing home setting.

By adulthood, most mentally retarded persons should have developed basic life skills and been prepared to assume a semi-independent or independent role in the community. For those who have not received adequate training and education, the residential program should place a major emphasis on teaching retarded adults to live as independently as possible and providing opportunities for them to develop their vocational potentiais.

Group Homes

The following are examples of residential programs for mentally retarded adults:

New Concepts for the Handicapped Foundation. "Normal community living" is the basis for the residential programs which are operated by Wisconsin's New Concepts for the Handicapped Foundation (NCHF). The Foundation is a nonprofit, tax-exempt corporation established

by the Association for Retarded Citizens in Wisconsin for the express purpose of developing and administering community alternative living situations. In order to obtain start-up monies, New Concepts surveyed residential needs and attempted to arrange various capital fund drives. As one might expect, lending agencies were reluctant to extend credit to a fledgling group with few tangible assets, no matter how philosophically sound. Basically, this program involves renting properties from investors under very specific conditions.

Because of the difficulty in obtaining capital funds, an investor-lease program was developed. Through this approach, residential services can be provided as quickly as needs are identified, without having to be concerned with capital outlay. Thus, the time delay usually experienced in capital fund drives is substantially reduced. Once appropriate property is secured, a home can become operational within a six-to-twelve week period of development. New construction can require an additional one and one-half to three months. The uniqueness of the lease which attracts the investor includes the following conditions:

- Rental is based at 12 percent per year of the total acquisition cost, assuring a reasonable profit for the investor.
- All taxes and special assessments are paid by the lessee (NCHF).
- All major repairs and replacements are the investor's responsibility for the first five years of the lease period. The lessee is responsible for maintenance and repairs after the initial five-year period.
- The investor supplies all major household furnishings and appliances, which are leased to NCHF at cost plus 10 percent interest over a 60-month lease/purchase period.

An initial general needs assessment is conducted prior to the time of construction or renovation of a facility. A more sophisticated assessment is later initiated to identify specific individuals who will live in the home under development. Professionals trained in behavioral management, social services and psychology carry out this evaluation. Once the home becomes operational, New Concepts has total responsibility for maintaining the residential program.

Wisconsin is divided into four New Concepts regions, each having a regional director appointed by the executive director. Additional administrative staff is provided on the basis of need, determined by a ratio of eight to 10 homes for each administrative position. The regional administrator is responsible for the overall hiring, training and supervision of all in-home staff (i.e., houseparents, relief staff and aides).

The in-home staff are responsible for the day-to-day operation of a group home. Community professionals assist in establishing the individual plan of care for each mentally retarded person. The live-in staff are each scheduled for 40 hours per

week, and they receive an additional allowance for overtime hours (called "reasonable agreement hours"), ranging from two to four hours per day, used to accomplish non-scheduled responsibilities such as bookkeeping, major shopping, minor home maintenance, etc.

In summary, New Concepts is unique in its ability to rapidly develop residential programs as a result of the investor-lease approach which, in turn, has caused it to be one of the largest non-profit entities of its kind serving the residential needs of retarded people.

Macomb-Oakland Regional Center. One of the most widely known, innovative community-based programs is operated by the Macomb-Oakland Regional Center in Mt. Clemens, Michigan. (As noted earlier, the Macomb-Oakland Regional Center also operates a foster home program for children.) The Regional Center is unique in that it serves as a catalyst in creating locally developed and administered community-based group homes throughout the state. The Center first encourages the establishment of a local non-profit organization which will operate one or more homes in a community. The Center contracts with the local agency in order to pay the costs of administering and operating the homes. It also helps the local organization to recruit qualified chief administrators.

An important aspect of the Regional Center strategy has been its emphasis on developing sound relationships within the community. The Center normally works with parents, attorneys, physicians or other people in the community who may not know a great deal about mental retardation but who have an essential interest in people. From this group it will form a board of directors. The staff are often recruited from the neighborhood in which the home will be located.

The maximum number of people living in a group home is six. The age range for group home clients is 15 to 90 years. Since most of the people placed by the Center are severely retarded, it is necessary to maintain a ratio of one staff person for every three clients; however, the ratio varies from program to program. Normally, at least two staff are on duty in the morning while people are getting up, having breakfast and getting ready to leave the home for their day programs. In the afternoons and evenings, when the residents come back from the day programs, there are again at least two staff, not counting any foster grandparents, volunteers or visitors who may be involved in activities within the home. There is always one staff member awake at night. On weekends there are at least two staff in the home in order to provide a variety of activities. Although the age range of staff members is 19 to 60 years of age, Jerry Leismer, Program Director for Macomb-Oakland Regional Center, notes that the homes tend to attract staff from young age groups, particularly college students.

All of the homes receive funds directly from the state. In addition, they utilize federal monies from Supplemental Security Income and Title XIX. During

1978, only two of the group homes were classified as ICF/MR facilities, although an increase is anticipated in that number in the near future.

The Macomb-Oakland Regional Center has developed an intensive in-service training program for the group home staff members, with regular updates on training methods. The Center has also developed a staff training manual which may be of interest to other groups involved in planning in-service programs.

Apartment Living

Many mentally retarded individuals can be prepared to live semi-independently or independently in apartment settings. The apartment concept generally represents the highest order of living arrangements in residential programming efforts. Beyond this stage would be total independent living and integration into the community.

The Hartford Apartments. The Hartford Regional Center, which was discussed in the previous chapter, operates three apartment complexes for mentally retarded adults, all of whom are former residents of the Mansfield Training School. The complexes collectively have 29 apartments which are designed to accommodate two persons in each. Most of the residents are mildly retarded, although some are moderately or severely retarded. On the average, each of them lived in the public institution about 15 years before being relocated to the community. Dan O'Conner, Superintendent of the Regional

Center, reports that a problem common to all of the apartment residents is inappropriate behavior which was learned during their stay in the institution. Thus, even after several years of living in the community, a relearning process is still in effect.

The residents pay rent on a sliding scale which is based on individual income levels. They are expected to pay for all of the needed services which their incomes will cover. Many of the competitively employed residents pay their total rent and buy their own groceries and clothes.

Each of the apartment complexes has a live-in couple who function as apartment managers. They are available to the residents for advice and counseling on an as-needed basis throughout the week and on weekends. There is no effort on the part of the live-in staff to actively supervise the residents.

The major type of assistance offered to the residents is in the area of leisure time activities. Serving the network of apartments is a corps of social workers and recreation specialists who are charged with the responsibility of developing a wide range of social and recreational activities which are all community oriented. Through such efforts, residents are encouraged to use community resources in the same manner that other people do.

The Regional Center's residential program provides maximum opportunity for residents to progress to living arrangements and lifestyles which require increasingly greater levels of independence. The agency has a full-time staff member who ensures that a full continuum of transitional residential services is available. Residents having the required capabilities can progress to subsidized independent living in apartments (e.g., settings funded by Housing and Urban Development Section 8 monies) or total independent living in apartments or houses.

Summary

The consensus among these programs for adults seems to be that establishing home-like environments whenever possible for residents is both cost-effective and developmentally supportive. Mentally retarded adults should be encouraged to function as nearly like all other adults in the community as they can. Productive work and enjoyable leisure time, the opportunity to make new friends and new choices and to experience new things are all essential to a well-rounded life for the retarded adult.

5

A FUTURE LOOK AT RESIDENTIAL SERVICES

During the past decade there has been a major increase in the number of community-based residential facilities for mentally retarded persons. Many options to the traditional institutional model have been developed during that period of time.

Unfortunately, the types of programs described in the preceding pages are not uniformly available throughout the country. Indeed, in many communities little or no progress has been made toward providing residential options for mentally retarded children and adults.

Residential services of the future will be positively or negatively affected by several social, political and economic conditions. Several anticipated trends were critically analyzed during a conference in 1978 which was sponsored by the Aid Association for Lutherans as a part of the ARC National Research and Demonstration Institute's AAL Project. Twenty-five nationally recognized experts in the areas of education, service delivery and government participated in the meeting. Although forecasting a future of increasing inflation, the conferees predicted a number of potentially positive outcomes in the area of residential services, including:

- a continuation of the decline in family size, which may make people more interested in becoming foster parents

- an increase in energy costs, which may reduce the size of dwellings, thus reducing the size of the typical foster family

- an increase in housing costs, which may make foster families, rather than group homes, more economically feasible

- a declining birth rate, which may decrease the number of non-handicapped children put up for adoption; consequently, potential adoptive parents may be more willing to accept handicapped children

- an increasing cost for running large institutions, which will cause a need for smaller residential units, including community-based facilities for all groups of retarded people

Some other expected future trends noted by conference attendees were:

- an increasing governmental awareness that in-home support for natural families is a cost-effective service approach, and a growing number of advocates for in-home placement

- a greater governmental and political interest in providing funds for the severely handicapped

- an increased tendency for funds to be directed toward individuals rather than agencies or programs. The client's dollar and how he or she chooses to spend it will become very important in future years.

Also, according to a Delphi* study (Roos, 1978), residential services in the United States will undergo major changes during the next 20 years. While a small majority of panel members felt that group homes within the community will become the primary residential model, two-thirds felt this development was undesirable because of problems they have in common with large institutions. All panel members agreed that extensive use of foster care and adoption was desirable, and predicted that these alternatives to institutional placement will be at least 10 times more common by 1985. It was also predicted that 25 percent more severely and profoundly retarded individuals will be retained in their own homes in the future, with increased help to parents by government-employed staff and homemaker services. The panel favored retention of retarded children in their own homes or in foster placements.

There are a number of critical concerns which must be addressed if this hopeful future is to be realized. Some of the major problem areas are:

- expansion of federal funding streams for community programs and support services

- development of state level commitment to the community approach to residential services rather than the large public institution

- stabilization of funding sources

- greater flexibility in funding sources

*The Delphi technique is a method for forecasting future trends and increasing the reliability and validity of expert judgments. It involves several rounds of predictions by a number of experts coupled with feedback regarding the group's responses at the end of each round.

- creation of more realistic fire and safety codes
- development of family subsidy programs
- expansion of foster parent programs
- development of respite care services for families who choose to retain retarded offspring in the home
- availability and coordination of support services in the community
- fostering positive social attitudes toward mentally retarded people in the community
- implementing realistic zoning regulations

Dealing with these issues will require the dedication and work of parents and advocates for mentally retarded people. It is clear that a promising beginning has been achieved, but much remains to be done. If past accomplishments serve as a valid guide, the future holds great hope for better meeting the residential needs of mentally retarded people.

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